

Structure and Process Evaluation
of an
APRN-Led Palliative Care Consultation Service

DOCTOR OF NURSING PRACTICE FINAL PROJECT

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by

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To my patients and their families

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"No man is an island entire of itself; every man is a piece of the continent, a part of the main; if a clod be washed away by the sea, Europe is the less, as well as if a promontory were, as well as a manor of thy friends or of thine own were . . ."

– John Donne, from *Meditation XVII*

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ABSTRACT

Purpose: The purpose of this project was to evaluate the structures and processes of the APRN-led Palliative Care at Grant consultation service in relation to the national guidelines developed by the National Consensus Project for Quality Clinical Palliative Care (NCP, 2009). **Methods:** The project was a cross-sectional case study of the views of the members of the Palliative Care at Grant team with respect to the appropriateness, presence, degree of implementation, and priority for attending to 39 criteria of Domain I: Structure and Processes of the NCP guideline. Demographic data were collected from the team. Evaluative data were collected using a modified form of an existing questionnaire. Once the data from the questionnaire were analyzed, a focus group interview was held to explicate the groups' thoughts on items that were of *high priority*. **Analysis:** The transcript was content analyzed to uncover recommendations for structure and process improvement and other issues to improve service. **Results:** Seven of eight participants returned questionnaires and five of eight participants attended the focus group. Of the 39 criteria, 38 were deemed appropriate to the service and of those, 32 were already present in the Palliative Care at Grant service. Twenty-seven recommendations were developed for implementing or improving 15 high-priority criteria. **Conclusions:** The service aligns with the consensus-based criteria, but work needs to be done to bring the service into full compliance. The results, implications for nursing and the alignment of this translational project with national goals for doctoral preparation for advanced nursing practice are discussed.

CHAPTER 1

INTRODUCTION

Palliative care maximizes quality of life for patients living with life threatening or serious illness from the time of diagnosis through the end of their lives (including hospice care) and then beyond for their survivors (Center for the Advancement of Palliative Care [CAPC], 2010a; Ferrell & Coyle, 2010; Meier, 2010; National Hospice and Palliative Care Organization [NHPCO], 2010; World Health Organization [WHO], 2010). Palliative care consultation services are proliferating in the U.S. to maximize the quality of the lives of patients in hospitals and the patients' families (Alliance for Excellence in Hospice and Palliative Nursing, 2010; CAPC, 2010b). Quality of life is improved for these patients and their families through the prevention and relief of suffering from physical, psychosocial, and spiritual needs, including pain and symptom management (WHO, 2010). The purpose of this project was to evaluate the structures and processes of the palliative care service at Grant Medical Center.

Nature of the Issue

The Palliative Care at Grant (PCG) service was established in 2004 to provide symptom management and support to admitted patients who are facing serious or life threatening illnesses and to their families. Grant Medical Center is a 340-bed hospital that is a Level I Trauma Center located in Columbus, Ohio (American Hospital Directory, 2010). The PCG team comprises four advanced practice nurses (APRNs = 4, FTE = 3.3) and support on a part-time basis from an administrative director, a medical director, an associate medical director, a registered pharmacist, and a chaplain. The team provides palliative care to patients in the hospital and their families by a robust inter-service referral process.

Grant's palliative care model was developed and implemented using an interdisciplinary team approach. Patients remain on the service of their attending physicians for curative treatment and disease management, but the PCG APRNs direct and supervise palliative patient care. Services

provided by the APRNs on the PCG team in addition to pain and symptom management include assisting with advance directives, code status changes, and discharge plans. The APRNs collaborate with all members of the team and with a variety of other health care professionals as is appropriate and necessary.

Available literature on palliative care cites the need for a systematic evaluation of any palliative care program that would focus on the quality of care from patient and healthcare providers' perspectives. At several points during the past seven years, the members of the PCG team have evaluated the program informally to improve service delivery (Feehan, 2010). No formalized evaluation, however, regarding the palliative care structure and processes has been done. Because of this lack, no quality could be documented, no comparisons could be made in relation to other programs, and no specific strategies could be created to direct the service's growth (Grembowski, 2001).

Significance of the Project to Nursing and Health Care

National consensus-based guidelines in palliative care have been written and refined over the past decade by several groups (National Consensus Project for Quality Palliative Care [NCP], 2009; National Quality Forum, 2004; National Cancer Care Network, 2008). This project used the lens of the National Consensus Project's *Clinical Practice Guidelines for Quality Palliative Care* (NCP, 2009) for program improvement. This guideline document was selected because consensus guidelines are among the strongest sources of evidence (Melnik & Fineout-Overholt, 2010; DiCenso, Bailey, & Haynes, 2009). Also, the Joint Commission (TJC) recently announced newly-created certification for palliative care programs (D. Meier, personal communication, March 17, 2011). The criteria for certification by TJC are likely to align with the NCP guideline document. This project may serve as a model, therefore, for other programs to build or realign their palliative care services with this national consensus guideline document and support certification efforts.

Among the priorities of the National Institutes of Health (NIH, 2010), the National Institute for Nursing Research (NINR, 2010), and the American Association of Colleges of Nursing (AACN, 2010) is improving end-of-life nursing care. In 1997, NINR was designated to lead NIH in end-of-life research efforts (NINR, 2010). End-of-life research continues to be a priority in the new NINR strategic plan (Woods, 2010). Because the core palliative care functions of the PCG team are provided by APRNs, the project aligns with national nursing practice, research, and educational priorities.

This project supports local healthcare goals. From the micro-system perspective, the project may inform improvements in the palliative care service at Grant consistent with Grant's strategic priorities for nursing (Grant Medical Center, 2009). From the macro-system perspective, Grant is a part of the OhioHealth system. The results of this project may be beneficial in developing a standardization of palliative care services across hospitals in the system.

With widespread attention on health care reform in the U.S., planned cuts in spending by third-party payer sources will result in a reduction in some services (Kaiser Family Foundation, 2010; Meier, Isaacs, & Hughes, 2010). Maintaining (or improving) quality of care in the face of reduced resources will be a challenge. High quality palliative care has been shown to reduce costs (Morrison et al., 2008). This project may contribute to improving the quality of health care delivered by the PCG team while potentially decreasing costs at Grant and at other hospitals in the OhioHealth system, and serve as a model for other hospitals and systems in the nation.

Project Objective and Questions

The objective of the project was to evaluate the structures and processes of the palliative care service at Grant Medical Center. The following questions were used to address the project objective:

1. How do members of the palliative care team view the appropriateness of applying each criterion in the *Clinical Practice Guidelines for Quality Palliative Care* (NCP, 2009) to their program?
2. What ideas do members of the team suggest about eliminating or changing structures or processes for those Domain I criteria that the team viewed as *present*, but *not appropriate*?
3. What ideas do members of the team suggest about improving existing structures or processes or adding new ones for those Domain I criteria that the team viewed as *high priority* and *appropriate* but as *not present* or *not fully implemented*?
4. How do members of the palliative care team view the alignment of the structures and processes of their program with the *Clinical Practice Guidelines for Quality Palliative Care* (NCP, 2009)?

CHAPTER 2

REVIEW OF LITERATURE

Theoretical Framework

Program evaluation is a process by which features of a service or course of action are compared to a set of standards, criteria, or objectives with the goal of product or process improvement, shift in strategy, or system changes (Rossi, 2004). Eager et al.'s framework (2003) was used to guide the project and the instrumentation selection (Table 1). The framework has two dimensions: level of evaluation and question to be answered. These dimensions indicate which tools are appropriate for a particular evaluative project. Because the focus of this project was the structures and processes of a system, the level of evaluation of interest in this project was 'Level III – Baseline, Process, and Outcome Indicators for Systems.'

Structures & Processes

The NCP guidelines are intended as benchmarks against which program components can be measured. For example, an important structural component for palliative care teams is the link with local hospice groups (Fernandes et al., 2010). Similarly an important process component in palliative care programs is the protocol for withdrawing life support (Kirchhoff & Kowalkowski, 2009). Both structure and process are referenced in Domain I. Because structural features and processes of palliative care programs have not been well studied, these guidelines present an opportunity to focus this evaluation on them.

Palliative care programs are typically structured with respect to the location where services are rendered. Palliative care teams draw from several disciplines (NCP, 2009) and are designed to meet the needs of patients and staff in high-, medium-, and low-acuity settings (Cheung et al., 2010; Kirchhoff & Kowalkowski, 2009). In-patient palliative care occurs either (1) in an acute care hospital unit, where the care is done by a specialty palliative care consultation team, or (2) in a dedicated palliative care unit in an acute care hospital, the health care team of which is specially

trained in the needs of palliative care patients. In the community, palliative care occurs in the home, skilled nursing facility, or long-term care hospital whereby a visiting palliative care team provides services, or in an outpatient clinic by a team of staff who see only palliative care patients (Ferrell & Coyle, 2010).

In-patient palliative care services have received the most attention with respect to outcomes (Bendaly et al., 2008; Dhillon et al., 2008; Fraiteh, et al., 2007; Gade et al., 2008; O'Mahony, Blank, Zallman, & Selwyn, 2005), but no comparative analysis of the various structures and models of care have been done. Additional research on structures and processes in palliative care is needed.

Palliative Care Program Evaluation

Palliative care program evaluation literature can be organized into two categories: outcomes and finances.

Outcomes

The outcomes literature has attempted to define those characteristics of patient care that correlate with the concept of good practices. These attempts have met with limited success (Pasman, Brandt, Deliens, & Francke, 2009; Zimmerman et al., 2008). Much of the research in palliative care outcomes focused on end-of-life care, i.e., the care of persons who are dying. This focus is due in part to the controversial findings of the landmark Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (Collins, Parks, & Winter, 2006; The SUPPORT Principle Investigators, 1995) that pointed to the need for additional interventions for supporting patients and their families when the patient is dying. Evaluating outcomes in palliative care is difficult because patients die. Patients who are released from the hospital but are not in the final stages of their lives can respond to customer satisfaction phone calls and questionnaires. Studies that interview bereaved family members of patients who have died cannot focus on the

patients as primary sources. Using the bereft as secondary sources often leads to skewed results confounded by the survivors' grief (Dean & McClement, 2002).

Death of a patient is often viewed as a failure by some healthcare providers. A "good death" (e.g., one in which the patient is not suffering) is viewed in palliative care settings, however, as a positive outcome (Ferrell, 2010). A shift in paradigm might be necessary to support palliative care outcomes research.

Proponents for the use of palliative care suggest that persons' quality of life is improved when this care is instituted. However, research in this area is lacking. Length of survival after discharge has been used to evaluate palliative care services (Brumley et al., 2007) as have rates of readmission after discharge from the hospital (Steer, Gibson, & Bourke, 2010). But the factors that confound the outcome variables were not controlled in these studies.

Some outcome studies show that palliative care services can improve patient and family well being (Siegert, Gao, Walkey, & Higginson, 2010) and can increase patient satisfaction regarding hospital stays (Lorenz, et al., 2008). Palliative care has been shown to relieve discomfort associated with cancer and non-cancer diseases (Addington-Hall & Higginson, 2001; Hui et al., 2010). The outcome of palliative care is centered on relief of symptom distress with particular emphasis on adequate pain management. Other symptoms that require attention include prevention of nausea and vomiting, dyspnea and respiratory depression, and existential crises (Protus, Schuster, & Grauer, 2008). Most outcomes evaluations centered on improving patient and family customer service scores (Bakitas et al., 2009).

The literature on palliative care has not addressed characteristics of the patients and families who are receiving palliative care services. This lack of attention to patients and their families have made comparisons of outcomes across palliative care services difficult to ascertain because without it, there is no baseline of comparison (Meier, 2010). Research is needed to

develop more evidence-based approaches to palliative care (Ferrell & Coyle, 2010; Prince-Paul & Daley, 2008).

Finances

Existing research on palliative care indicates that this care will reduce certain costs related to patient care (Ferrell & Coyle, 2010). Although palliative care reduces patient length of stay in some instances, it is not a reliable single measure of overall cost savings. Palliative care services have been shown to save hospitals money by reducing or eliminating the use of costly in-patient services such as intensive care and step-down, using lower cost pharmacologic alternatives, and reducing unnecessary lab tests (Edens, Harvey, & Gilden, 2008; Smith & Cassel, 2009).

Summary

In summary, evaluating palliative care services is difficult. Although the outcomes from pain and symptom management can be evaluated at the bedside, program evaluation is more elusive. New consensus guidelines are intended to serve as a platform for evaluating palliative care services, but they have not been so used to date. Because many palliative care patients die, secondary sources of information have been used. Characteristics of these secondary sources and their relationship to patients' experiences have not been studied. Evaluations of the impact of palliative care on finances have been inconclusive, focusing on length of stay. The literature on costs avoided by engaging palliative care services, however, is just beginning to emerge. Using the guidelines to evaluate palliative care programs warrants exploration.

CHAPTER 3

METHODS

This project was a cross-sectional case study to evaluate the structures and processes of a palliative care service. A questionnaire and a subsequent focus group interview were used to obtain data. (Eager, Cranny, & Fildes, 2004; Stommel & Wills, 2004; Waltz, Strickland, & Lenz, 2010). The proposal for the project was approved by The Ohio State University Behavioral and Social Science Institutional Review Board and the OhioHealth Institutional Review Board #2 (Doctors/Grant/Marion).

Sample

The participants were a purposive sample that comprised all members of the palliative care team who agreed to participate. The sampling unit was the team ($n = 1$). The team was selected because members understood the palliative care program. The use of the team met the intent of the project objective because the focus was on evaluation of internal structures and processes. The size of the group ($n = 8$) was ideal for the focus group approach (Stommel & Wills, 2004; Waltz et al., 2010). All eight members of the PCG team were recruited and gave informed consent to participate in the study.

Instruments

A demographics questionnaire, an evaluative questionnaire, and a focus group interview protocol were the instruments used in this project.

The Demographics Questionnaire

Understanding the demographic characteristics of the PCG team will help the reader to develop a sense of the context in which this project took place. Acknowledging the heterogeneous and homogeneous nature of the culture of the team informs its world view and thus its approach to patients and their families (Warren, 2005). Because cultural competency is a component of the

structure and process criteria for quality palliative care, these data were collected in addition to the evaluative data. (See Figure 1 in the appendix.)

The Evaluative Questionnaire

Eager et al.'s (2004) framework required an instrument that would be a self-assessment of an existing palliative care consultation service. The Coalition for Compassionate Care (now the Supportive Care Network, SCN; McSkimming, Myrick, & Wassinger, 2000) developed such an instrument that Eager et al. (2003) modified for their use. The SCN questionnaire comprised 68 items organized into 12 clusters. The stems of the items were the evaluative criteria. The participants were asked a question about each criterion: Is the criterion present or not present in the program (*P = present, NP = not present*)? They were also asked to rate the degree to which the criterion is implemented in the service being evaluated (on a scale of 0 = *not at all* to 10 = *fully implemented*) and to rate their priority for future action (on a scale of 0 = *not at all – no action required* to 10 = *undertake as a matter of urgency*). For example, one of the items clustered as a Practice Standard is "Cultural/religious guidelines are integrated." If cultural or religious guidelines are integrated into the program under evaluation, the answer to the present/not-present question is *P for present*.

Since the development of the SNC tool, NCP (2009) developed a new set of criteria for quality palliative care programs. For this project, the SNC tool was modified to incorporate these new criteria as follows: First, the criteria statements from the NCP document relevant to structure and processes (Domain I) replaced the stems in the previously-developed questionnaire. Second, because one of the project questions asked how the members of the team view the appropriateness of each criterion to the palliative care service, a fourth question (column) was added: "Is this criterion appropriate to be applied to this service?" The levels of this variable were *appropriate* and *not appropriate*. The resultant evaluative questionnaire appears as Figure 2 in the appendix. A pilot test of the modified questionnaire to calculate reliability as a component of stability was

outside the scope of this project. Prior to using the questionnaire in the project, it was reviewed by the author's project committee for face validity.

The Focus Group Instrumentation

The instrumentation for the focus group was an interview protocol that guided the discussion. Krueger and Casey (2009) suggested a schema for developing focus group questions. The opening question breaks the ice and begins to make participants feel comfortable. Transition questions help the participants to begin to identify with the topic of the focus group and serve to bridge to the key questions. The key questions reflect the core of the research questions to be answered. The ending question signals closure of the focus group discussion.

The key questions for this project reflected the possible response combinations for each criterion based on the levels of the four scales. Once the results of the evaluative questionnaire were known, the author determined that only the criteria with *high priority* would be discussed in the focus group due to time constraints and unpredictably high demands on the PCG team due to increased census. (See Figure 3 in the appendix.)

Data Collection

The data collection occurred in two separate sessions. The first was the completion of the questionnaires and the second was the focus group. The participants consented to one two-hour session for each of two weeks during the data collection, for a total of four hours.

The demographic and evaluative questionnaires were distributed to consenting participants and collected for analysis. The schema by Krueger and Casey (2009) guided the focus group process. Opening, transition, key, and ending questions were used. The focus group centered on team member thoughts about the high-priority items in the guideline uncovered in the analysis of the questionnaire data. During the focus group, the author read the instructions (Figure 4), led the focus group discussion, and took notes. The session was audio recorded. A research nurse not

affiliated with the team coordinated the tape recorder and assisted with the session. The notes were used to elucidate the questionnaire data and to uncover themes after transcription.

Data Analysis

The Demographic & Evaluative Questionnaire Data

The raw data were reviewed by the Chair of the author's committee prior to and during the analysis process. The data from the questionnaires were entered into a spreadsheet for analysis. To ensure data quality, the raw data were printed in a report and compared against the questionnaires from which they were derived. Any discrepancies were noted and changes were made in the spreadsheet.

The analysis of the data from the questionnaires used descriptive techniques. Because the data for the questions "Is the criterion present or not present in the program?" and "Is this criterion appropriate to be applied to this service?" were categorical, modes were calculated for each item on both scales. The scales for the other two rating categories collected data on continuous variables, so mean scores were calculated. Data points that were left blank or were unreadable were considered missing and were reported, but not included in the analysis.

The results were reviewed. The criteria viewed as appropriate to the work of the team (operationalized as modal appropriateness score = *appropriate*) and of a high priority (operationalized as a mean priority score > 5) that were either not present (operationalized as modal presence score = *not present* and labeled "to be implemented") or are not fully implemented (operationalized as mean implementation score < 10) shaped the discussion. Items not fully implemented, but with a mean implementation score > 5 were labeled "needing some improvement" and those with a mean score < 6 were labeled "needing a great deal of improvement."

The Focus Group Data

The author's views and biases were bracketed prior to the interview process so they did not influence the focus group process. The audio recording from the focus group session was transcribed by the author using Dragon Naturally Speaking software (Nuance Communications, 2011). All methods and procedures were described in detail and an audit trail was kept to document the sequence for data collection and analysis. The data from the focus group interviews were reviewed by the Chair of the project advisory committee.

Content analysis. The content for analysis was the transcript of the focus group interview. NVivo 9 software (QSR International, 2011) was used to assist with the content analysis due to its functionality, accessibility to the author, and its ease of use. The words were the unit of analysis because an aim of the analysis was to achieve stability (Waltz, et al, 2010). All words were used to classify phrases, sentences, paragraphs, and dialog segments. First, a word count was generated and reviewed. The top 10 substantive words were used to create the initial nodes. As the author traversed the transcript, he moved textual elements one by one into either an existing node or into a new node. At the end of the transcript, the author scrutinized the nodes, rearranged them, and clustered them based on their meaning as he interpreted the meaning within the context of the research questions. The process repeated until all of the text was coded and the author and the project advisor were satisfied that the hierarchy of themes was a satisfactory representation of the transcript (Graneheim & Lundman, 2003). Members of the palliative care team were consulted regarding appropriateness of themes. Recommendations for program improvement were developed based on the themes that emerged in the analysis and specific suggestions made during the focus group.

CHAPTER 4

RESULTS

The objective of the project was to evaluate the structures and processes of the palliative care service at Grant Medical Center. Seven of the eight team members (87.5%) completed the questionnaires and handed them in. The range in age of the participants who completed their questionnaires was 31 years to 69 years, the mean age was 51 (*S.D.* = 11.9) years, and the median age was 53.5 years. The participants were primarily Caucasian subjects ($n = 7$, 87.5%) who reported some sort of Christian-related spirituality or religion ($n = 7$, 87.5%). The majority of the participants reported that they were married or lived with another adult ($n = 6$, 75%), and the majority reported their sexual orientation as heterosexual ($n = 7$, 87.5%). The majority of participants identified themselves as English-only speakers ($n = 7$, 87.5%) and they reported that they spent the majority of their developmental years in settings that ranged from rural areas to urban areas of varying complexity and size. Due to competing priorities, only five of the eight members of the team participated in the focus group. Three non-nurse participants were absent from the focus group for undisclosed reasons and another non-nurse participant was present for only the last 20 minutes of the session. One non-nurse participant stepped out of the room for about three minutes and one APRN left the room for about five minutes to answer phone calls.

Question One

How do members of the palliative care team view the appropriateness of applying each criterion in the *Clinical Practice Guidelines for Quality Palliative Care* (NCP, 2009) to their program? The team evaluated 38 of the 39 criteria (97.4%) as appropriate to the PCG service (see Figure 2 in the appendix for the text of each criterion). Hospice staff had always been welcomed and invited to come to PCG team meetings, but PCG staff should not pursue attending hospice meetings:

... Although I think that it's appropriate for them to be here when they can...I don't know it necessarily make sense for palliative to be a member of the hospice meetings...

Recommendation

1.8.e.1 Re-extend the invitation to the hospice liaison to attend daily morning meetings of the PCG team and to attend weekly team meetings:

Do you think it might be something to pursue again like getting ... somebody ... to come to some of our team meetings? / Well they're always invited.

Question Two

What ideas do members of the team suggest about eliminating or changing structures or processes for those Domain I criteria that the team viewed as *present*, but *not appropriate*? No items that were evaluated as *present* in the current PCG service were judged as *not appropriate*.

Question Three

What ideas do members of the team suggest about improving existing structures or processes or adding new ones for those Domain I criteria that the team viewed as *high priority* and *appropriate* but as *not present* or *not fully implemented*?

Criteria to be Implemented

The participants evaluated all but six of the *appropriate* criteria as *present* in the PCG service (32 out of 38, or 84.3%). Four of these six were *high priority* "to be implemented": 1.3.d, 1.6.d, 1.6.g, and 1.7.b. They called for the development of respite services; the development of a quality improvement program; and the creation of written policies and procedures.

Recommendations.

1.3.d.1. Research for scalability how one provider provides pseudo-respite care services:

Hospice offers respite here at Grant and I was thinking... it would be nice if there was respite capabilities for patients to come in for also.

1.6.d.1. Determine the feasibility of working with the Quality Office to garner resources:

You know, because a lot of these teams have quality people 'cause there is a quality management program... We don't have the time to see all the patients let alone go around and do quality measures on them.

1.6.d.2. Investigate the use of electronic tools for gathering quality improvement data:

But, you could see what kind of options would be available to you electronically... or you know there are ways that you could pull that out electronically.

1.6.g.1. Discuss with the Quality Office the need to get input from the community:

Any ideas? 'Cuz I hear quality that's what I'm thinking: her quality office.

1.6.g.2. Operationalize a quality improvement activity related to referral sources:

I wonder ... about an evaluation tool for ourselves that we can use among the physicians services and our referral sources so we can have feedback on...

1.6.g.3. Coalesce data from undergraduate nursing students who have been precepted by

PCG APRNs:

[The teachers of the undergraduate nursing students we precept] ask them about their rotation with us. So we could ask for a summary of those.

1.6.g.4. Coalesce data on feedback from precepted medical residents:

[The director of Grant Medical Education] could probably send us that information and if we don't like the way it's written maybe we could do our own thing.

1.7.b.1. Create a policies and procedures (P&P) manual specifically for PCG team:

You know, a manual... I know that we have a checklist of things that we go through. But were the policies were actually included in the manual you know how you have the manual?

1.7.b.2. Use an interdisciplinary approach to the development of the P&P manual:

That makes sense. So it's not just our policies but it's also how does it interface with Grant and with OhioHealth or wherever or however far we can take that.

1.7.b.3. Request information sharing visits from allied services and colleagues:

And, ah, I think it would do us well to, um, ask them maybe to come and talk to us about that because we do it all the time...

Criteria Needing a Great Deal of Improvement

Five of the *present* items were evaluated as "needing a great deal of improvement," three of which were designated as *high priority*. These three high-priority criteria were 1.3.f, 1.5.a, and 1.8.f, and called for regular team meetings; continuing education resources and opportunities; and the involvement of community providers (palliative care, hospice, and others) to promote increased access across the continuum.

Recommendations.**1.3.f.1** Reinstate daily huddles:

I think that was my interpretation that it's not regular enough... where we could have a sit down okay every Tuesday morning at 8:30 let's just rehash what's going on for the week. Do we have any concerns?

1.3.f.2. Document discussions during daily huddles:

...if you're not able to attend the meeting then you're responsible for reading the minutes and signing off on it that you've read it... have everybody sign off on minutes if you're not able to go. ... Then you would have those available to go back to in case there are questions also. / I mean, it could be something as easy as a notebook.

1.5.a.1. Search for educational and CPE opportunities that do not include travel:

So it's definitely something to continue to get our administrator's support on but then also find ways to learn about other things. Because there may be other things like web stuff that we don't have to really travel for or something like that you know something we can do on our paper days...

1.8.f.1. Improve relationship and communication with hospice:

Strengthening things with [Grant's hospice liaison].

1.8.f.2. Investigate an outpatient palliative care service:

I think it would be great to have an outpatient palliative care clinic. And that would help in that part of the continuum... The patients would have somewhere for symptom management outside of the hospital. We currently don't have that. / ...that's where you're gonna get the CHF folks, the COPD folks to not go into exacerbation.

1.8.f.3. Re-invigorate linkage with Grant's CHF clinic:

I know they help them with symptom management. But I imagine there's not much help with planning for end-of-life and spiritual assistance. I mean, I would imagine that those are not things that are covered in the CHF clinic. ... But that may be another opportunity.

1.8.f.4. Reinforce collaboration with Continuity of Care staff (RN CMs & social workers):

I feel like at least I feel like we've got a good case management system here and ... the case managers and the social workers are key to providing the care across the continuum...

Criteria Needing Some Improvement

Most of the *present* items were viewed as "needing some improvement," seven of which were designated as *high priority*. These seven high-priority criteria were 1.1.e, 1.3.a, 1.3.b, 1.3.h,

1.6.a, 1.6.c, and 1.7.a. They addressed regular assessment review; the interdisciplinary team; qualifications of team members; documented policies for timely response to referrals; pursuit of excellence; regular and systematic quality improvement activities, assessments, and performance reviews; and emotional support for the PCG team members.

Recommendations.

1.1.e.1. Develop and implement review process at huddles or team meetings:

But if you don't meet as a team to discuss the patients other than when you're meeting with the physicians it's a different focus when you meet with our physician ...

1.3.a.1. Reinforce consistent attendance at team by all members of the team:

And I find that the biggest value of having our team meetings. But again it's not fully interdisciplinary. You know, I don't get the, um, necessarily... 'cuz people come, you know, show up at different times. Like sometimes somebody will be there or not. So, I don't get the full picture.

1.3.a.2. Establish a consistent day of the week and time for weekly team meetings:

...because of our schedules were not all, not everybody on the team is able to attend our team meetings all the time.

1.3.b.1. Encourage continuous learning after orientation:

... just because you have finished orientation process, does not mean that you are expert. I think it's always good and I think it's maybe different individual to individual.

1.3.h.1. (See above for ideas about developing a policies & procedures manual.)

1.6.a.1. Regularly reinforce the pursuit of excellence:

I think the first part... the first sentence is a given... that the commitment is there. It's that long last sentence about regular and systematic measurement, analysis, review, evaluation, goal-setting, and revision...

1.6.a.2. (See above for engaging with the Quality Office.)

1.6.c.1. (See above for engaging with the Quality Office.)

1.7.a.1. Talk with EAP about available resources to support PCG staff:

That's what I was thinking, the EAP. We can get that.

1.7.a.2. Discuss options with Behavioral Health:

Are the psych mental-health specialists available to staff for crisis situations where they've cared for somebody for a long time and it's really a heavy emotional blow to the staff member? Are they available to help them with coping?

1.7.a.3. Investigate a retreat or spa day; consult with administration about options:

I was thinking it would be nice in an ideal world if we could just have a retreat somewhere for a whole day just to go and rejuvenate somehow somewhere... You know, once a month or once every three months... I mean, to really get the batteries recharged somehow

Question Four

How do members of the palliative care team view the alignment of the structures and processes of their program with the *Clinical Practice Guidelines for Quality Palliative Care* (NCP, 2009)? The content analysis shed additional light onto the overall perceptions of the relationship between the NCP Guidelines and the work of the PCG team. Commentary first clustered into two primary themes: *Internally-Focused Matters* and *Externally-Focused Matters*. Because this project addressed internal structures and processes, only *Internally-Focused Matters* are presented.

Internally-Focused Matters

The theme *Internally-Focused Matters* clusters around three constructs: operational, administrative, and clinical issues.

Operational issues. The operational issues that emerged were concepts of stress of a demanding job, the role of the team, and within-team communication.

Stress. The concept of stress emerged as an operational issue due to the intensity of the various emotional demands of the work of the PCG team.

And one of the things that I think has been weighing on us as, as our acuity and everything gets higher and more intense, is that we do have a very demanding job. I mean, from the minute we get there we're running. The theme internally focused matters clustered around three constructs administrative issues clinical issues and operational issues

Role. Operationally, the concept of role emerged: The team found strength in their role as consultants and not as primary service for PCG patients:

Well, I think, too, we're considered a consultant. It's not that we're an attending service. ... I don't see us needing to be... We're not operating that way.

The participants expressed frustration about the poor connection between responsibility for length of stay and the limited authority to make the discharge decisions:

When we talk about length of stay, it's not a good reflection of our effectiveness... because we don't make the discharge decisions.

Within-team communication. Communication between members of the PCG team emerged as an operational issue. Morning huddles are used inconsistently to share information and to receive feedback from colleagues:

I think we do a good job of talking about clinical practices in our team meetings and then maybe a little bit in our lunches and in our huddles if we have them in the morning spontaneously. But I'm not so sure we do it all regularly and systematically.

At other times, patients and individual nursing practice are discussed:

We even work through lunch, you know, we talk about cases over lunch although we do talk about a few other things sometimes.

Administrative issues. Concepts that related to administrative types of issues emerged during the content analysis. Adding tasks to the work of the team is perceived as worthy only if the payoff offsets the investment. In spite of the relative worth of recruiting a new APRN, however, another limitation is that not many APRNs had come forward to apply for vacancies.

Recruiting. Finding professional advanced practice nurses to recruit for this specialized and demanding work is difficult:

And we're not very successful at finding team members very readily, either.

Cost-benefit ratio. Many opportunities for team members to participate in activities other than direct patient service, irrespective of the potential for return on investment, are not worth the necessary sacrifice of billable time:

There's value to it but perhaps not enough value to offset the cost of dollars and resources.

Clinical issues. Concepts related from clinical issues that emerged from the focus group interview centered on maintaining the quality and accessibility of the PCG service.

Accessibility. The concept of accessibility was discussed in the context of the provision of palliative care services around the clock, every day of the year. The administrative director has held firm for quite some time that 24 x 7 palliative care service is not a priority for her from a resource and recruitment perspective, which was referenced during the focus group interview:

I know the 24 hours a day, seven days a week access (our administrator) has said we're not going to do or she doesn't support or things like that, um.

The participants came to consensus that 24 x 7 coverage might not be appropriate at Grant:

So really it's not a high priority for us to implement something like that, correct? / Mm-hmm.

Interdisciplinary team. Some quality issues centered on the concept of the interdisciplinary team. Team meetings are rarely attended by every affiliated member of the PCG service so true interdisciplinary care planning, review of care, and team building does not occur:

When I worked with hospice, we really had team meetings which were so beneficial. You'd present the patient and everybody around gave their feedback. (The pharmacist) would talk about the meds, and the nurse who was taking care of the patient would say whatever and the [physician] would say whatever. I mean, it was so well-rounded and you really got a great picture about everything...

Evaluation. The participants expressed the need to evaluate their quality of care:

I wonder, and I throw this out to everybody, about an evaluation tool for ourselves that we can use among the physicians services and our referral sources so we can have feedback on... about our practice, about timeliness, about management of the patient...

But, in spite of the hospital's regular customer satisfaction program, the participants expressed frustration of not having access to the PCG patients for quality improvement projects:

And there's no way they want to change it. (The administrative director) asked a couple times right up front. And they will, they will not budge. So that's a no-no. That won't happen come hell or high water. We could not keep a list of our own patients and send them our own surveys. That was not allowed.

Continuing education. Another clinical issue that emerged was that of support for and accessibility of continuing education opportunities:

I wonder... It would be nice if there could be ways to get more opportunities for all of us to do those things. Be it through flyers or online. It would be nice to share it around and...

Additional Themes

As the analysis continued, two additional themes emerged orthogonal to those described above and cross-cutting almost all of them: impact of limited resources and impact of poor communication.

Impact of limited resources. The first cross-cutting theme that emerged was the impact of limited resources on the work of the team:

And then time, then resources and then resources, money. So... Same old saw I guess, huh?

The world is getting tighter and tighter in healthcare.

Time. Available time to do the needed work emerged:

I think there's a fair amount of decent ideas in here, but time seems to be our biggest enemy.

I think that's a common theme that's coming up. Time. Time.

Insofar as quality is concerned, time limits the team's ability to develop a quality assessment and evaluation program. Because the APRNs are busy seeing patients and attending to the needs of families, no time remains in the work day to develop and implement one:

We don't have the time to see all the patients let alone go around and do quality measures on them.

Also, the participants expressed that limited time constrains opportunities to consult one another on their individual approaches to caring for their patients:

Well, in the busy-ness of the days, I think we're [discussing patients] less.

Time constrains participation of every discipline in team meetings, thus limiting the ability to develop care plans that address the full spectrum of palliative care:

Because of our schedules were not all, not everybody on the team is able to attend our team meetings all the time. So we may lose perspective on something, or an opportunity.

Finances. Limited financial resources impact the work of the team by limiting the ability to grow a truly interdisciplinary team:

And because we don't have a social worker on our team... our palliative care team doesn't do that.

Cascading from the impact of limited resources on staff growth is the decrease in flexibility in time away from the hospital for personal and professional growth opportunities, thus also having a negative impact on morale:

I know again staffing becomes a concern because you have somebody gone and it's hard for the people left behind.

Financial resources also constrain the team's ability to contract with other services to assist with quality assessment and improvement efforts:

So really it's not a high priority for us to implement something like that, correct? / Right. I just think it would be unrealistic. If we had all the money in the world... maybe back in the 60s or 70s, yeah, but...

Impact of poor communication. The second cross-cutting theme that emerged was the impact of poor communication on the work of the team:

I think we do a good job of talking about clinical practices of our team meetings and then maybe a little bit in our lunches and in our huddles if we have them in the morning spontaneously. But I'm not so sure we do it all regularly and systematically.

This theme described problems with communication among and between groups that are central to the work of PCG: between the team and other services at Grant, and between individuals who are members of the PCG team. Needs of patients and families, needs of the healthcare team, and needs of the organization cannot be met without effective communication.

Other hospital services. Communication issues with respect to other services at the hospital emerged:

Legal had a definite idea and was pretty definite and emphatic about what could and what could not be withdrawn on comfort measures. And it seemed to have, to differ from what we practice.

APRNs at Grant are out of the communication loop with nursing administration, are not linked with nursing's shared governance infrastructure, and are not invited to the table when

important policy issues are discussed. This disconnect has a direct impact on how PCG does its work because the members of the team must spend time they do not have to follow up on ad hoc comments to which they are exposed in the hospital:

But I think we are a big enough presence in this hospital and we need input into all those policies and procedures that run through that [Nursing] Congress.

And I know that our administrator has asked for, like when I get anything from the nursing office to share it with everybody in the whole cancer services team.

Neither do they have the opportunity to provide input from their years of experience in nursing to improve the quality of nursing care:

I know that when I sat on that, I had lots of suggestions and I don't think that should be discredited.

With respect to quality issues, PCG has not been allowed to participate in the hospital's organized nursing customer service initiatives:

We have tried from the get-go and they have this outside agency that does the surveys and they will not modify their program.

Isolation. Two identified factors contribute to the APRNs on the team feeling isolated from one another, thus making internal communication difficult: independence and workload.

Independence. Because they are advanced practice nurses, they work independently out in the hospital instead of with a cadre of co-located colleagues:

I have felt very isolated...I have.

Workload. Heavy workloads deny the APRNs time to talk with one another about their patients and their practices, thus adding to the feeling of isolation:

You have so much acuity and so much pressure that there are opportunities to improve....

Discussion and Conclusions

Discussion

Consensus-based guidelines are among the strongest evidence sources available to guide healthcare practice (Melnik & Fineout-Overholt, 2010; DiCenso et al., 2009). The NCP (2009)

guidelines, however, fall short in that they do not prescribe an evaluative methodology to operationalize their application. This project described one such methodology, of modifying existing instrumentation and using it to evaluate an existing APRN-led consultation service.

The participants indicated that almost all of the criteria were appropriate to the PCG service and none should be discontinued. These results could be due to the service's alignment with the literature and existing international knowledge base about palliative care when the service was originally established in 2004 (personal conversation, Elaine C. Glass, CNS, July, 2009). The APRNs on the team are also quite active in professional development and attending national and international meetings related to palliative care. They bring that information back with them to incorporate into the operations of the service. They expressed a desire to increase their participation in professional development and look forward to brainstorming some additional routes to bolster their work-related knowledge and linkages with professional colleagues.

The majority of the criteria were evaluated as appropriate to the service, present in PCG, and implemented fairly well, needing only some attention to bring them to full implementation. The seven of these criteria that were evaluated as high priority speak to quality linked with the interdisciplinary nature of the team and the emotional needs of that team, as well as the timeliness of the services rendered by the team. The professionals with more of their time dedicated to palliative care end up spending some of their time performing some social work roles or counting on social workers in other services to fill in the gaps for them.

Gathering data on how the team precepts undergraduate nursing students and medical residents would inform the team's educational role (Hospice & Palliative Nurses Association, 2005). Because the PCG service so rarely precepts APRNs-in-training, no recommendations were developed to coalesce evaluative data from APRN students. An opportunity to become more involved with APRN students, however, is on the horizon when a local college begins admitting

students to its newly-created master's degree adult CNS program that emphasizes palliative care. These students will need placements and PCG would be an ideal placement for them.

The work of the palliative care team is demanding and draining. An effort to streamline tasks and to improve documentation could serve to relieve some of the pressure individuals reported. As independent practitioners some members of the team expressed feeling isolated, thus having a negative impact on their work. Team building exercises or caring rituals done as a team may mitigate some of these stressors.

The criteria that needed a great deal of improvement seem to link quality to written policies and regular, proactive communication. Communication channels could be blocked for several reasons. Without written policies members of the team might be practicing in divergent patterns that dissuade those with whom they interact from receiving clear and consistent messages about the PCG service. Because the PCG service is not an attending service but rather a consultation service the expectations of those with whom they communicate might differ from the team's understanding of their role. The culture in the hospital is that the attending service has the final say in any patient matter. So care recommendations by the PCG team must align with the plan of care as developed by the attending service. In the best of all possible scenarios, the PCG team will be involved in care planning along side of the attending, including discharge planning.

Also, hospital- and system-level policies about interacting with patients and their families after discharge stymie the team's ability to collect quality improvement data from their most important constituents: patients and their families. These policies thwart at some level communication channels between the APRNs on the PCG team and the nursing service at large. Finally, because this palliative care service is not operationally linked with one particular hospice program, collaboration and partnerships are difficult across the continuum outside of the defined scope of this service. Continuity of care when the patient leaves the hospital is at risk because of the

lack of coordination between community-based health care providers and those who work exclusively in the hospital setting.

The impact of limited resources was viewed as restricting the growth of the program, the quality of the service delivered, the morale of the staff, and the ability of the PCG team to meet all of the national quality guidelines.

Conclusions

Conclusions related to project outcomes and methodological issues are as follows. The PCG service aligns with criteria in the national consensus-based guidelines for quality clinical palliative care, but not 100%. All criteria were supported as appropriate except for members of PCG attending staff meetings of local hospice services. Recommendations for improving services were developed. Whether or not these recommendations can be implemented as described is a matter of resources and priority on behalf of not only the team but also stakeholders external to the team within the hospital and within OhioHealth. The administrative director, for example, holds the responsibility for the budget of the PCG team, but is restricted in the number of staff she is allowed to add annually. The limited availability of time and financial resources stunts the ability of the program to improve with respect to the national guidelines. Communication among members of the team and among the team and other services is important to the success of the program. Whereas the team might be able to change internal communication patterns, shifting internal expectations and other characteristics of the team to facilitate communication with other services and other constituents may not be a complete solution.

Evaluating the structures and processes of APRN-led, inpatient, palliative care consultation service using national consensus-based guidelines for quality care is possible. Translating existing instrumentation and methodology from other palliative care evaluation projects has been demonstrated and would be strengthened by replication. Techniques used in the project can be used to evaluate with rigor nursing practice from a structures and process perspective and

recommendations for aligning the practices of palliative care services with national consensus-based guidelines can emerge from a project such as this.

CHAPTER 5

SUMMARY

Purpose. The purpose of this project was to evaluate the structures and processes of the APRN-led Palliative Care at Grant consultation service in relation to the national guidelines developed by the National Consensus Project for Quality Clinical Palliative Care (NCP, 2009). This was achieved.

Questions. The four questions answered in this project were:

How do members of the palliative care team view the appropriateness of applying each criterion in the *Clinical Practice Guidelines for Quality Palliative Care* (NCP, 2009) to their program? All but one criteria (38 out of 39, or 97.4%) were appropriate to the service.

What ideas do members of the team suggest about eliminating or changing structures or processes for those Domain I criteria that the team viewed as *present*, but *not appropriate*? No criteria were so viewed. All 36 of the present criteria were viewed as *appropriate*.

What ideas do members of the team suggest about improving existing structures or processes or adding new ones for those Domain I criteria that the team viewed as *high priority* and *appropriate* but as *not present* or *not fully implemented*? Recommendations were developed from the focus group discussion.

How do members of the palliative care team view the alignment of the structures and processes of their program with the *Clinical Practice Guidelines for Quality Palliative Care* (NCP, 2009)? The members of the team viewed all but six of the *appropriate* criteria (32 out of 38, or 84.3%) as *present* in the current service.

Methods. A printed questionnaire followed by a focus-group interview. For each of 39 items, participants responded in writing to four questions. The subsequent focus group interview transcript was content analyzed for recommendations and themes.

Sample: A purposive sample of eight members of the Palliative Care at Grant team including APRNs and others.

Results. The project report presented recommendations for implementing or improving high-priority criteria that were appropriate to the PCG service and other emerging themes.

Limitations of the Study

The results of this evaluation project are limited to the Palliative Care at Grant service only, not any other palliative care service, and at one point in time only. It was restricted to Domain I: Structures and Processes of the NCP guideline document, and did not address Domains II through VIII (NCP, 2009). Because the subjects were a purposive sample, the results cannot not be generalized to any population. The process, however, might be useful to guide other programs in their evaluative efforts.

Implications for Nursing Practice

Translational nursing research is the application of basic nursing research to a practical situation (Woods & Magyary, 2010). The evaluative framework, instrumentation, and methodological approach of this project are an instantiation of translational nursing. Plus, the results may be translated to evaluate other inpatient palliative care consultation teams. The teams may be located in other hospitals within OhioHealth, within other health-care systems, and in other settings in which people experiencing serious or life-threatening illnesses and their families require symptom management and support. Such translation would not only provide evaluative information to the programs themselves, but would enable meta-analysis or aggregation of results to provide the broader picture of the quality of palliative care at the micro, macro, and mega system levels (Meier, 2010).

The leading role of advanced practice nurses in palliative care is also affirmed by this project from a structure and process perspective. Because all but one criterion were deemed appropriate to this team, the Domain I criteria are applicable to the APRN-led interdisciplinary model, not just the predominant physician-led model (CAPC, 2010a). The project, therefore, supports the development of other APRN-led inpatient consultation services for palliative care in other venues, too.

Consistent with clinical nursing research and education goals, this project demonstrates a translational nursing research project that aligns with national standards for doctoral education for advanced nursing practice (AACN, 2006): Components of the scientific underpinnings of palliative care practice, including pain & symptom management; palliative care organizational and systems leadership for quality improvement; systems thinking with respect to service improvement, translation to other venues, and the fit to system goals at the micro, macro, and mega levels; clinical scholarship and analytical methods for evidence-based practice by translating the evaluative framework and by making sense out of the collected data; information systems/technology for the improvement and transformation of health care by using computer-based analysis software and voice recognition; interprofessional collaboration for improving patient and population healthcare outcomes through the engagement of the interdisciplinary team; clinical prevention and population health for improving the nation's health by addressing structures and processes for improving quality of life of persons living with severe and life-threatening illness; and advanced nursing practice by virtue of the service under investigation being APRN-led.

The development of this translational project serves not only as an evaluation of one particular palliative care service, but it may serve as a framework for other nurse researchers and educators of future nurses as they engage in both practice and research at the bedside, contributing to the health and well-being of others while contributing to the betterment of their profession.

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Appendix.

Table 1. The evaluation framework (adapted from Eager et al., 2003).

This diversity of palliative care research has important implications for the design of an evaluation. Rather than a "one size fits all" approach, palliative care evaluation needs to be responsive, flexible, multi-pronged, and tailor-made to the particular activity being evaluated. The following evaluation framework guides the task of tailor-making each evaluation

EVALUATION HIERARCHY	SERVICE/PROJECT DELIVERY What did you do?	SERVICE/PROJECT IMPACT How did it go?	SUSTAINABILITY Can you keep going?	CAPACITY BUILDING What has been learned?	GENERALIZABILITY Are your lessons useful for someone else?	DISSEMINATION Who did you tell?
Level 1: Impact on and outcomes for consumers (patients, families, carers, friends, communities)						
<i>Baseline, Process & Outcome Indicators</i>	<ul style="list-style-type: none"> Plans, reports, routine data Qualitative data 	1.1 Patient / client palliative care stage of illness data set 1.2 Patient / client experiences – patient questionnaire 1.3 Patient / client experiences – staff completed questionnaire 1.4 Carer experiences with palliative care 1.5 Community awareness of palliative care 1.6 Community awareness: remote aboriginal and Torres Strait Islander Communities.	4. Sustainability Tool	5. Capacity Building Tool	6. Generalizability Tool	7. Dissemination Log
Level 2: Impact on and outcomes for providers (professionals, volunteers, organizations)						
<i>Baseline, Process & Outcome Indicators</i>	<ul style="list-style-type: none"> Plans, reports, routine data Qualitative data 	2.1 Palliative care providers 2.2 Volunteers currently working in palliative care 2.3 New palliative care volunteers 2.4 People ending their time as a palliative care volunteer 2.5 Health professionals not working in palliative care services 2.6 Health workers in remote aboriginal and Torres Strait islander communities	4. Sustainability Tool	5. Capacity Building Tool	6. Generalizability Tool	7. Dissemination Log
Level 3: Impact on and outcomes for the system (structures and processes, networks, relationships)						
<i>Baseline, Process & Outcome Indicators</i>	<ul style="list-style-type: none"> Plans, reports, routine data Qualitative data 	3.1 Palliative care service self-assessment 3.2 General health care organizational survey 8. System level impacts and outcomes	4. Sustainability Tool	5. Capacity Building Tool	6. Generalizability Tool	7. Dissemination Log

Note: The evaluation tools included in this figure are discussed in the toolkit.

The Demographic Questions – Please answer all questions with very short answers.

What was your age at your last birthday (in years)?	
How would you describe the locale in which you spent most of your developmental years (e.g., ages birth to 21 years)?	
How would you describe your ethnicity?	
How would you describe your spirituality or religion?	
How would you describe your sexual orientation?	
How would you describe your personal relationship status (e.g., single, married, partnered. . .)?	
How would you describe your living situation (e.g., live alone, live only with another adult, live with another adult and one or more children. . .)?	
What was your first language?	
If you are fluent in one or more languages other than English, which one(s)?	
With what other aspects of your personal culture do you identify that you would care to divulge here?	
If you have any comments, please add them here.	

Thank you for your kind assistance with my project.
Now, please turn in this form and complete the other questionnaire.

Figure 1. The demographics questionnaire.

Palliative Care Service Evaluation

Domain I: Structure & Processes

	<u>Column A</u> A = Appropriate NA = Not Appropriate	<u>Column B</u> P = Present NP = Not Present	<u>Column C</u> 0 = Not at All True 10 = Fully Implemented	<u>Column D</u> 0 = Not a Priority for Future Action 10 = Undertake as a Matter of Urgency
Guideline 1.1 The timely plan of care is based on a comprehensive interdisciplinary assessment of the patient and family.				
1.1.a Assessment and its documentation are interdisciplinary and coordinated.				
1.1.b Initial and subsequent comprehensive assessments are carried out through patient and family interviews, review of medical records, discussion with other providers, physical examination and assessment, and relevant laboratory and/or diagnostic tests or procedures. The consultative evaluation should include the patient's current medical status, adequacy of diagnosis and treatment consistent with review of past history, diagnosis and treatment, and responses to past treatments.				
1.1.c Assessment includes documentation of disease status, including diagnoses and prognosis; comorbid medical and psychiatric disorders; physical and psychological symptoms; functional status; social, cultural, spiritual, and advance care planning concerns and preferences, including appropriateness of referral to hospice.				
1.1.d Patient and family expectations, goals for care and for living, understanding of the disease and prognosis, as well as preferences for the type and site of care, are assessed and documented.				
1.1.e The assessment is reviewed on a regular basis.				
Guideline 1.2 The care plan is based on the identified and expressed preferences, values, goals, and needs of the patient and family and is developed with professional guidance and support for decision making.				
1.2.a The care plan is based upon an ongoing assessment determined by goals set with patient and family and with consideration and discussion of the changing potential benefits and burdens of care along with assessment at critical decision points during the course of illness. Family is defined by the patient and may include relatives or friends.				
1.2.b The care plan is developed with the input of patient, family, caregivers, involved healthcare providers, and the palliative care team with the additional input, when indicated, of other specialists and caregivers, such as school professionals, clergy, friends, etc.				
1.2.c Care plan changes are based on the evolving needs and preferences of the patient and family over time and recognize the complex, competing, and shifting priorities in goals of care.				
1.2.d The interdisciplinary team coordinates and shares the information, provides support for decision making, develops and carries out the care plan, and communicates the palliative care plan to patient and family, to all involved health professionals, and to the responsible providers when patients transfer to different care settings.				
1.2.e Treatment and care setting alternatives are clearly documented and communicated and permit the patient and family to make informed choices.				

Figure 2. The evaluative questionnaire.

(continued)

	Column A A = Appropriate NA = Not Appropriate	Column B P = Present NP = Not Present	Column C 0 = Not at All True 10 = Fully Implemented	Column D 0 = Not a Priority for Future Action 10 = Undertake as a Matter of Urgency
1.2.f Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence, and patient/family preferences. Reevaluation of treatment efficacy and patient-family preferences is documented.				
1.2.g It is essential that the evolving care plan is documented over time.				
Guideline 1.3 An interdisciplinary team provides services to the patient and family consistent with the care plan. In addition to nursing, medicine, and social work, other therapeutic disciplines with important assessment of patients and families include physical therapists, occupational therapists, speech and language pathologists, nutritionists, psychologists, chaplains, and nursing assistants. Complementary and alternative therapies may be included.				
1.3.a Specialist-level palliative care is delivered by an interdisciplinary team.				
1.3.b The team includes palliative care professionals with the appropriate patient-population-specific education, credentialing, and experience and the ability to meet the physical, psychological, social, and spiritual needs of both patient and family. Of particular importance is hiring physicians, nurses, and social workers “appropriately trained” and ultimately certified in hospice and palliative care. Education should include a fundamental understanding of the domains of palliative care and the goals of the Medicare Hospice Benefit, in addition to pain, symptoms, grief, bereavement, and communication. Ideally this occurs in preceptorships, fellowships, or in baccalaureate and graduate specific programs. Continuing education is an essential for professionals currently in practice.				
1.3.d The patient and family have access to palliative care expertise and staff 24 hours a day, seven days a week. Respite services are available for the families and caregivers of adults with life-threatening illnesses.				
1.3.e The interdisciplinary team communicates regularly (at least weekly or more often as required by the clinical situation) to plan, review, and evaluate the care plan, with input from both the patient and family.				
1.3.f The team meets regularly to discuss provision of quality care, including staffing, policies, and clinical practices.				
1.3.g Team leadership has appropriate training, qualifications, and experience.				
1.3.h Policies for prioritizing and responding to referrals in a timely manner are documented.				
Guideline 1.4 The use of appropriately trained and supervised volunteers within the interdisciplinary team is strongly encouraged.				
1.4.a If volunteers participate, policies and procedures are in place to ensure the necessary education of volunteers and to guide recruitment, screening (including background checks), training, work practices, support, supervision, and performance evaluation and to clarify the responsibilities of the program to its volunteers.				
1.4.b Volunteers are screened, educated, coordinated, and supervised by an appropriately educated and experienced professional team member.				

Figure 2. The evaluative questionnaire, continued.

(continued)

	Column A A = Appropriate NA = Not Appropriate	Column B P = Present NP = Not Present	Column C 0 = Not at All True 10 = Fully Implemented	Column D 0 = Not a Priority for Future Action 10 = Undertake as a Matter of Urgency
Guideline 1.5 Support for education and training is available to the interdisciplinary team.				
1.5.a Educational resources and continuing professional education focused on the domains of palliative care contained in this document are regularly provided to staff, and participation is documented.				
1.5.b This education also should comply with federal and state licensure and credentialing regulations.				
Guideline 1.6 In its commitment to quality assessment and performance improvement, the palliative care program develops, implements, and maintains an ongoing data driven process that reflects the complexity of the organization and focuses on palliative care outcomes.				
1.6.a The palliative care program must be committed to the pursuit of excellence and the highest quality of care and support for all patients and their families. Determining quality requires regular and systematic measurement, analysis, review, evaluation, goal setting, and revision of the processes and outcomes of care provided by the program.				
1.6.b Quality care must incorporate attention at all times to: <ul style="list-style-type: none"> • Safety and the systems of care that reduce error. • Timeliness – care delivered to the right patient at the right time. • Patient-centered care, based on the goals and preferences of the patient and the family and also inclusive of the principles of family-centered care. • Beneficial and/or effective care, demonstrably influencing important patient outcomes or processes of care linked to desirable outcomes. • Equitable care that is available to all in need and all who could benefit. • Efficient care designed to meet the actual needs of the patient so that it does not waste resources. 				
1.6.c A quality assessment and performance review is done across all the domains including organizational structure, education, team utilization, assessment and effectiveness of physical, psychological, psychiatric, social, spiritual, cultural, and ethical assessment and interventions. From this, the palliative care program establishes quality improvement policies and procedures.				
1.6.d Quality improvement activities are routine, regular, reported, and are shown to influence clinical practice. While the palliative care organization leadership is responsible for such programs, there are designated individuals who operate the quality assessment and performance improvement program.				
1.6.e The clinical practices of palliative care programs reflect the integration and dissemination of research and evidence of quality process.				
1.6.f Quality improvement activities for clinical services are collaborative, interdisciplinary, and focused on meeting the identified needs of patients and their families.				
1.6.g Patients, families, health professionals, and the community may provide input for evaluation of the program.				

Figure 2. The evaluative questionnaire, continued.

(continued)

	Column A A = Appropriate NA = Not Appropriate	Column B P = Present NP = Not Present	Column C 0 = Not at All True 10 = Fully Implemented	Column D 0 = Not a Priority for Future Action 10 = Undertake as a Matter of Urgency
Guideline 1.7 The palliative care program recognizes the emotional impact on the palliative care team of providing care to patients with life-threatening illnesses and their families.				
1.7.a Emotional support is available to staff as appropriate.				
1.7.b Policies guide the support of staff and volunteers, including regular meetings for review and discussion of the impact and processes of providing palliative care.				
Guideline 1.8 Palliative care programs should have a relationship with one or more hospices and other community resources to ensure continuity of the highest-quality palliative care across the illness trajectory.				
1.8.a Palliative care programs must support and promote continuity of care across settings and throughout the trajectory of illness.				
1.8.b As appropriate, patients and families are routinely informed about and offered referral to hospice and other community-based healthcare resources.				
1.8.c Referring physicians and healthcare providers are routinely informed about the availability and benefits of hospice and other community resources for care for their patients and families as appropriate and indicated. Policies for formal written and verbal communication about all domains in the plan of care are established between the palliative care program, hospice programs, and other major community providers involved in the patients' care.				
1.8.d Policies enable timely and effective sharing of information among teams while safeguarding privacy.				
1.8.e Where possible, hospice and palliative care program staff routinely participate in each other's team meetings to promote regular professional communication, collaboration, and an integrated plan of care on behalf of patients and families.				
1.8.f Palliative and hospice care programs, as well as other major community providers, routinely seek opportunities to collaborate and work in partnership to promote increased access to quality palliative care across the continuum.				
Guideline 1.9 The physical environment in which care is provided should meet the preferences, needs, and circumstances of the patient and family to the extent possible.				
1.9.a When feasible, care is provided in the setting preferred by the patient and his or her family.				
1.9.b When care is provided away from the patient's home, the care setting addresses safety and, as appropriate and feasible, flexible or open visiting hours, space for families to visit, rest, eat, or prepare meals and to meet with the palliative care team and other professionals, as well as privacy and other needs identified by the family.				
1.9.c The setting should address the unique care needs of children as family members or visitors.				

Please add any additional comments you would like to make. Continue on the back of this page if needed.

Figure 2. The evaluative questionnaire, continued.

The Focus Group Questions**Opening Question**

1. Please tell us your code number and your role on the Palliative Care at Grant team.

Transition Questions

1. How long have you been involved in palliative care in general and at Grant?
2. How did you get involved in palliative care in general and at Grant?
3. Was the questionnaire a good measure of the structure and processes of the Palliative Care at Grant service?

Key Questions

Using the results from the questionnaire to guide selection, one or more of the following questions will be asked:

1. The results indicated that this criterion is not present and should be implemented. Why is that so? Do you agree? Why or why not? What should be done?
2. The results indicated that this criterion is present but needs some / a great deal of improvement. Why is that so? Do you agree? Why or why not? What should be done?
3. The results indicated that this criterion is not appropriate to the service, but is present to some degree. Should we stop doing this? When should we stop? How?
4. The results indicated that this criterion is not appropriate to the service and is not present. Should any action take place with respect to this? Why or why not? If so, what?
5. The results indicated that this criterion is present in the service but not implemented. How can this be? What should be done?
6. The results indicated that this criterion is not present but needs some / a great deal of improvement. How can this be? What should be done?

Ending Question

1. Is there anything else you would like to say about the results of the questionnaire or the structure and processes of the Palliative Care at Grant Service?

Figure 3. The focus group questions.

The Focus Group Instructions

Author : "Thank you again for agreeing to participate in this program evaluation of the Palliative Care at Grant service. Please remember that you are free to remove yourself from the study at any time by letting me know.

"As you are aware, today's session will be audio taped. I would like to introduce Ms. X. She will be helping me to record your responses and will be minding the audio tape so I do not have to worry about it.

"After processing the results from the questionnaires you completed earlier, I have developed a set of questions that I would like to discuss with you. First, I would like to set a few ground rules.

1. Because the conversation is being audio taped, I would ask that you speak clearly and distinctly and not talk over one another. Please do not hold side conversations.
2. Please put your pagers and your cell phones on vibrate.
3. This session will last no longer than two hours and we will not be taking a scheduled break. If you must leave, please do so quietly. We will announce for purposes of the audio tape if anyone leaves the room or comes into the room after our conversation begins.
4. You have been provided a pad of paper and a pencil to jot notes to yourself during the conversation. Please leave all notes, pads, and pencils in the room at all times and do not take them with you at the end of the session.
5. You have each been randomly assigned a number that is on the tent in front of you. To protect each participant's identity, please do not use each others' real names. If you must address another participant, please use the number that is in front of that person.
6. Because I am a member of the team, I will be participating in the conversation as well as leading the discussion. Please refer to me as 'Twelve.'

"Do you have any questions? Let's begin. Ms. X will now start the audio tape."

Figure 4. The focus group instructions.